



Bringing Early Hearing Detection and Intervention (EHDI) to Minority Populations

Overview

As the number of minority individuals in the United States increases, so does the number of babies being born to minority women. Many of the factors that are common among minority communities, such as poverty, low levels of education, language barriers, and lack of health insurance, can leave children born to minority mothers at risk for birth defects and developmental disabilities, as well as late diagnosis and delayed enrollment in intervention programs for children with special health care needs.

- In 2005, the U.S. minority population totaled 98 million, or 33 %, of the country's total population of 296.4 million¹ and it is estimated that in 2050 this population will increase to become half of the U.S. population.²
- The number of babies born to minority mothers accounted for more than 40% of the total births in 2003.³
- Fertility rates for Hispanic women were approximately 40% higher than those for non-Hispanic Black or African-American women, and more than 45% higher than those for women in all other racial and ethnic groups.³
- Approximately 47 million Americans speak a language other than English at home, and 21.4 million of these have limited proficiency in English.⁴
- In 2004, 33% of Black or African-American children and 29% of Hispanic children younger than 18 years of age lived in families with incomes below the official poverty threshold.⁵
- In 2003, 34% of the Hispanic and 35% of the Native American population younger than 65 years of age had no health insurance.⁵
- In the 2004 school year, minority students with hearing loss represented 50% of the total deaf or hard-of-hearing population receiving special educational services in the United States.⁶

Introduction

Early Hearing Detection and Intervention (EHDI) programs across the United States play an essential role in helping to identify children born with hearing loss before 1 month of age. Unfortunately, in the year 2004 only approximately half of the children whose screening was positive were reported to have received recommended follow-up services (e.g., diagnostic audiologic evaluation). These babies experienced what is called "loss to follow-up".

Factors predicting noncompliance with recommended follow-up are predominantly sociodemographic, including:

- Non-White race
- No health insurance
- Young maternal age
- More than two children at home
- Late onset of prenatal care⁷

Strategies

To help address the "loss to follow-up" issue, it is important for EHDI programs to reach diverse populations. The following suggested strategies can be used by states to help educate minority families about the importance of hearing screening and the EHDI process.





1. Culturally sensitive educational materials should be developed for each minority population.

Many states have educational materials translated into different languages. Often, these tools are literal translations from English rather than culturally appropriate products able to fulfill the informational needs of the target populations.

- Effective educational materials tools must address the needs of each minority community as they are perceived by residents.⁸
 - Minorities should be included in the design and implementation of their educational materials through focus groups, surveys, and interviews.
 - People fluent in the language and familiar with the culture of the target minority group should be included in the development and translation of any materials for this group.
- Educational tools need to be modified to meet the requirements of the minority culture. Not everyone or every culture thinks and comprehends in the same way.
 - Appropriate words and phrases that are familiar to each specific group should be used.
 - Educational materials should be written in a way that reflects not only the level of education, but also the culture and learning style of the community. Characteristics such as socioeconomic status and beliefs about health and religion need to be considered.
 - Pictures and images that reflect the culture of the target group should be used.
 - A format that will capture the attention of members of the target group should be used.
- The materials must be tested with members of the target population to ensure that they are appropriate and effective.



2. Additional resources should be offered so that members of minority groups can find more information on EHDI.

Most of the EHDI materials (e.g. brochures and booklets) that have been translated into other languages do not include a telephone number where non-English-speaking parents or those with low English proficiency can call and ask for more information. Most of these numbers are available only for English-speaking people.

- If a state program has difficulty providing an operator full-time who speaks the minority language, there are others options that can be used:
 - A telephone line can be created with a recorded message in the appropriate language that can be monitored by someone who speaks the language and who can call back with the requested information.
 - Some health departments have telephone numbers where general information in other languages, such as Spanish, is available. Information about EHDI can be added to these numbers.
 - Minority parents can be provided with resources, such as links to minority organizations or a list of places where they can find information or assistance in their native language.



3. Information about EHDI should be disseminated within minority communities

Health programs dealing with topics such as child immunizations, breast feeding, and child development are often well-known by families. To ensure EHDI is also recognized within diverse minority communities, it is important for states to:

- Identify and engage key community partners. Potential partners should reflect the diversity of the community and should include:
 - Minority families of children with hearing loss.
 - Minority health care providers.
 - Health care professionals and institutions serving minorities.
 - Community-based health and social service agencies.
 - Advocacy or social organizations serving minorities.



- Disseminate information in different languages through media resources, such as Spanish language television (TV) and newspapers in different languages. Some minority populations might prefer to get information through the TV, radio, or newspaper. Contacting the local newspaper or radio or TV station might be a good method to explore this possibility.



4. Families with low English proficiency should be educated about EHDI.

Some minority families might come from countries where newborn hearing screening is not offered, and they might not be aware of the importance of having their newborn tested for hearing loss. Many of these families might have literacy difficulties even in their native language. For these families it is important to have someone available who can speak their language to inform them about the EHDI program. While bilingual minority health care providers are the most desirable choice for communicating with families of low English proficiency, the limited availability of such services often calls for alternative solutions.⁹

- Certified interpreters
 - Successful interpretation sessions require that the interpreters have a clear understanding of the intent of the communication and desired outcome. It is important for the EHDI health care providers to speak with the interpreters and explain the purpose of the meeting before they see the family.
- Bilingual staff
 - Before using a bilingual staff member as an interpreter, it is important to be aware of state law and regulations about who can perform medical interpretation.
 - Bilingual staff should be appropriately trained before they can provide interpretation services. They should also be knowledgeable about the EHDI program before they meet with families.
- Over-the-phone interpretation
 - Telephone interpretation services should be used only as a supplemental system when an interpreter is needed instantly or when services are needed in an unusual or infrequently encountered language.

- If telephone interpreters are used at all, procedures and policies should be in place to facilitate the use of these telephone lines, and staff should be trained in their use.



5. EHDI data on race, ethnicity, and language spoken at home should be collected by each state.

The CDC EHDI program works with states to develop systems that can help EHDI programs collect important data on race and ethnicity and the language spoken at home. This data will be helpful in:

- Allocating resources.
- Conducting research to learn more about hearing loss in minority populations. Previous research has shown that:
 - The occurrence of middle ear infections is highest among Native Americans.
 - The prevalence of congenital sensorineural hearing loss is higher among children with minority or lower socioeconomic status, or both.¹⁰



6. The resources available within the community should be maximized.

It is usually difficult for minority families of children with hearing loss to find resources such as educational tools written in their native language or bilingual health care providers who can provide them with the necessary information to make informed decisions for their children. Resources can be created to help minorities overcome these difficulties. For example:

- Parents of children with hearing loss from different cultural backgrounds can be trained to serve as interpreters and guides to assist other families through the EHDI system.
- Support groups that include members from minority populations can be an excellent resource for new families.



7. The particular needs of the target population should be determined.

The process of finding information and making decisions can be highly complex for minority families of children with hearing loss.¹¹ Minority families often have to contend with additional issues, such as how to communicate with their children in multiple languages. These languages include American Sign Language (ASL), English, and their own native language. This must be addressed when providing information to minority populations.

- It can be difficult for minority families to understand how different intervention programs assist a child whose primary language is not English. Providing additional information to families can provide them a better knowledge of how to help their children with hearing loss.
- The goal of any EHDI program should be to educate and provide minorities with sufficient information to make informed decisions for their children with hearing loss.

References:

1. U.S Census Bureau. Nation's Population One-Third Minority [press release]. Washington, DC; 2006 May 10.
2. U.S Census Bureau. Interim projections consistent with Census 2000: US interim projections by age, sex, race and Hispanic origin. Washington, DC: US Department of Commerce; 2004.
3. Hamilton BE, Martin JA, Sutton PD. Births: Preliminary data for 2003. National vital statistics reports; vol 53 no 9. Hyattsville, MD: National Center for Health Statistics. 2004.
4. U.S Census Bureau. Census 2000 brief: Language use and English-speaking ability: 2000. Washington, DC: US Department of Commerce; 2003.
5. National Center for Health Statistics. Health, United States, 2005 with Chartbook on Trends in the Health of Americans. Hyattsville, Maryland: 2005.
6. Gallaudet Research Institute. Regional and National Summary Report of Data from the 2004-2005 Annual Survey of Deaf and Hard of Hearing Children and Youth. Washington, DC: GRI, Gallaudet University; 2005.
7. Folsom, RC. Identification of neonatal hearing impairment: Recruitment and follow-up. *Ear and Hearing* 2000; 21(5): 462-70.
8. Bronheim S, Sockalingam S. A guide to choosing and adapting culturally and linguistically competent health promotion materials. Washington, DC: National Center for Cultural Competence, Georgetown University Center for Child and Human Development; 2003.
9. Office of Minority Health. National Standards for Culturally and Linguistically Appropriate Services in Health Care. Washington, DC: U.S Department of Health and Human Services; 2001.
10. Stern, RE. Recent epidemiology of pediatric cochlear implantation in the United States: Disparity among children of different ethnicity and socioeconomic status. *The Laryngoscope*. 2005; 115(1): 125-31.
11. Steinberg, A, Bain, L. A look to the decisions Hispanic families make after the diagnosis of deafness. Washington DC: Laurent Clerc National Deaf Education Center, Gallaudet University; 2002.

For more information, please visit the CDC-EHDI website, which has answers to commonly asked questions, research findings, and data and information for parents (also available in Spanish) and professionals <http://www.cdc.gov/ncbddd/ehdi>.

Cultural Competence Within Early Hearing Detection and Intervention Service Delivery Systems

Program Checklist

This checklist can be used to heighten awareness of your agency's policies and procedures when working with culturally and linguistically diverse populations.

- My agency or program incorporates cultural competence in its mission, goals, and values.
- My agency or program has a policy for handling inappropriate language or behaviors by staff members that are based on race, ethnicity, sex, ability, or sexual orientation.
- My agency or program has policies that ensure that the cultural and linguistic backgrounds of the clients it serves are taken into consideration when providing services.
- My agency or program actively recruits employees from diverse cultural and linguistic backgrounds.
- My agency or program collects Early Hearing Detection and Intervention (EHDI) data on races, ethnicities and languages spoken at home.
- My agency or program has a list of agencies and health care providers (audiologists, speech language pathologists, pediatricians, etc.) who are qualified to work with the diverse cultural and linguistic communities in my state.
- My agency or program has a list of available certified interpreters.
- My agency or program facilitates meaningful participation of diverse consumers and communities in planning, delivery, and evaluation of services.
- My agency or program supports ongoing professional development and in-service training (at all levels) for awareness, knowledge, and skills in the areas of cultural and linguistic competence.
- My agency or program ensures new staff members are provided with training, technical assistance, and other supports necessary to work within culturally and linguistically diverse communities.
- My agency or program ensures culturally competent bilingual staff members are provided with training, technical assistance, and other support necessary to provide patients with appropriate information about the EHDI process.
- My agency or program has written materials or information that meets the cultural and linguistic needs of the communities it serves.
- My agency or program has a toll-free number staffed by qualified employees who speak the native languages of the communities it serves.